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ABSTRACT

Several patient status variables have been associated with caregiver burden. A study was conducted to examine relationships between caregiver burden; patient variables of cognitive status, depression, and physical status; and caregiver perceptions of disruptive behavior and discrepancies between patient abilities and behaviors. Subjects were elderly psychiatric patients (N=46) referred to a geriatric assessment unit and their caregivers (N=46). Patients completed measures of cognitive status, depression, and self-reported ability to perform basic activities of daily living (walking, eating) and instrumental activities of daily living (doing laundry, talking on the telephone). Caregivers completed measures of patient disruptive behavior, caregiver distress, and caregiver burden. The results revealed that significant predictors of caregiver burden were patient disruptive behavior, patient activities of daily living limitation, patient memory or orientation, and caregiver distress. These results, along with results from previous studies, suggest that predictors of caregiver burden vary with the elderly patients' diagnoses. A three-page reference list and four data tables conclude the document. (NB)

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Elderly Psychiatric Patient Status and Caregiver Perceptions as Predictors of Caregiver Burden[1]

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RUNNING HEAD: Caregiver burden

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Abstract

Aspects of patient status and caregiver perceptions considered to be important contributors to caregiver burden, were examined in a sample of elderly psychiatric patients referred to a geriatric assessment unit and their caregivers. Significant predictors of caregiver burden were patient disruptive behavior, patient ADL limitation, patient memory/orientation (MMSE), and caregiver distress. These results, along with previous studies suggest that predictors of caregiver burden vary with the elderly patients' diagnoses.

Key Words: Caregiver distress, depression, ADL/IADL, cognitive impairment

Elderly Psychiatric Patient Status and Caregiver Perceptions as Predictors of Caregiver Burden

Several patient status factors have been associated with caregiver burden. These include the elderly patient's level of physical limitations (Deimling & Bass, 1986; Grad & Sainsbury, 1968), inability to communicate (Fengler & Goodrich, 1979), a variety of disruptive behaviors, including night wandering (Deimling & Bass, 1986; Sanford, 1975) and aggression (Grad & Sainsbury, 1968). A recent review of factors affecting burden among cargivers of Alzheimer patients, however, has concluded that the patients' severity of illness, including cognitive status and functional problems, is not correlated with caregiver burden (Ory, Williams, Emr, Lebowitz, Rabins, Salloway, Sluss-Radbaugh, Wolff, and Zarit, 1985).

Grad and Sainsbury (1968) and Deimling and Bass (1986) found patients' level of confusion to be predictors of caregiver burden. In contrast, Zarit and his associates found little evidence of this relationship. One study, based on a sample of 29 caregivers of demented patients, concluded that patient cognitive impairment was not related to caregiver burden (Zarit, Reever, & Bach-Peterson, 1980). In another study of caregivers of demented patients, an <u>increase</u> in patient cognitive functioning was related to an <u>increase</u> in caregiver burden, (Zarit, Todd, & Zarit, 1986).

Similarly, the evidence is equivocal in regard to the relations

between caregiver burden and patients' limitations in self-care behaviors, such as basic physical activities of daily living (ADL) and instrumental activities of daily living (IADL). Grad and Sainsbury (1968) found psychiatric patients' inability to provide self-care predictive of caregiver burden. Deimling and Bass (1986) reported limitations in patient ADLs predictive of caregiver distress. Morycz (1985) also found that caregiver tasks involving higher levels of physical labor were related to likelihood of patient institutionalization in his sample of 80 caregivers of Alzheimer patients. In contrast, Zarit et al. (1980) did not find limitations in ADL or IADL to be related to caregiver burden. Gilhooly (1984) also found no relation between demented patients' cognitive and physical impairments and caregiver morale.

In regard to the relationship between caregiver burden and patients' disruptive behaviors, the evidence is also equivocal. Again, Zarit et al. (1980) did not find patient behavior problems (e.g., neglecting self care, restlessness) to be related to caregiver burden (e.g., decrement in caregiver's health, well-being, relationship to patient). In contrast, Diemling and Bass (1986) found disruptive behavior (e.g., patient swearing, interfering with others' privacy) to be related to four aspects of caregiver burden in a sample of 586 caregivers and their patients. These aspects of burden included negative family relationships, restrictions in caregiver activity, decrement in caregiver health, and caregiver depression.

Given these equivocal findings based on relatively few studies, the purpose of this study was to examine further the relationship between caregiver burden and patient status in a sample of elderly psychiatric patients. Patient depression was included in addition to examining the relationships between caregiver burden, patient status variables (cognitive impairment, ADL, IADL) and caregiver reports of patient disruptive behavior. Patient depression was included for two reasons: 1) a significant proportion of elderly psychiatric patients are referred for problems of depression (Redick & Taube, 1980); and 2) a patient's withdrawal and refusal to be active in their care may be seen as distressful to the caregiver as disruptive behaviors. To parallel this latter idea, a measure of caregiver perceptions of patient limitions and/or discrepancies in ability and behaviors was also obtained. Thus, relationships were explored between caregiver burden and patient variables of cognitive status, depression, physical status (ADL and IADL), and caregiver perceptions of disruptive behavior and discrepancies between patient abilities and behaviors.

Method

Patient Sample. Fifty-one patients at a geropsychiatry assessment unit were initially asked to volunteer in the study. Their participation in the study included consent to contact their caregiver. Referral problems in the sample included depression (54%), possible dementia (24%), anxiety (10%), hypomania (4%), medication problems (4%), and unspecified (4%). The average length of stay was

31.4 days (S.D. = 2.4). The average age of the patients was 75.9 (S.D. = 7.7). Thirteen were men (26%) and 38 were women (74%).

Caregiver Sample. Fifty-one caregivers were asked to complete a mailed questionnaire consisting of the caregiver perception measures listed below. Fourty-six of the caregivers agreed to participate. Table 1 shows the relationship of the caregivers to their elderly psychiatric patient. A majority of the caregivers are daughters (39%), a pattern consistent with previous reports (e.g., Brody, 1981; Stoller, 1983). The average length of caregiving was two or more years.

Table 1 about here

Measures. The cognitive status of patients was assessed by the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The MMSE has adequate concurrent validity, test-retest reliability, and inter-group sensitivity among elderly persons who are normal, depressed, or demented (Folstein, et al., 1975). Patient depression was assessed by the Geriatric Depression Scale (GDS; Yesavage, Brink, Rose, Lum, Huang, Adey & Leirer, 1983). The GDS is considered to be a single factor scale, with concurrent validity with Zung (Zung, 1965) and Hamilton (Hamilton, 1960)depression scales; it has discriminant sensitivity among normal, moderately, and severely depressed persons (Yesavage, et al., 1983).

Patients' self-reported ability to perform Activities of Daily

Living (ADL; Katz & Akpom, 1976) such as the ability to walk or eat, as well as Instrumental Activities of Daily Living (IADLs), such as the ability to talk on the telephone or do laundry, were gathered. Patients were asked whether they could perform eight ADLs and nine IADLs without help (scored "0"), with some help (scored "1"), or whether they were completely dependent on others help (scored "2") for each of the 17 activities. ADL and IADL have been incorporated into numerous other comprehensive assessments; the reliability and validity of these scales are considered sufficient to warrant their use in clinical assessment, program evaluation, and health planning (Katz, 1983).

Caregiver report of Patient Disruptive Behavior was measured by Deimling and Bass' (1984) Mental Status questionnaire, which is designed to tap areas of patient functioning believed to be troublesome to caregivers. Included in the scale are disruptive behaviors such as patient confusion, poor social functioning, and complaints and criticism of the caregiver. Caregivers were asked how frequently the behaviors occurred (0 = not at all, 1 = sometimes, 2= most of the time).

Caregiver Distress was measured by a series of items parallel to patient ADL and IADL items, developed with the hypothesis in mind that caregivers will be frustrated by the patient's refusal to perform activities they are capable of doing, and/or frustrated by the patient's performance of activities that they should not do for safety

reasons. In the questionnaire, the caregiver was first asked to estimate whether the patient was capable of executing each of the 17 ADL/IADL activities (yes or no) and then whether the patient actually performed the activities (yes or no). Next to each estimate the caregiver was asked to rate their degree of distress over discrepancies (or lack of discrepancies) between patient abilities and activities, or safety hazards, on a three point scale (0 = not at all distressed, 1 = somewhat distressed, 2 = very distressed). Responses were summed and designated Caregiver Distress.

Caregiver Burden was measured with the Relatives' Stress Scale (RSS; Greene, Smith, Gardiner, & Timbury, 1982). The RSS was developed through factor analysis, and test-retest reliability is considered satisfactory (Greene, et al., 1982). Nine items tapping areas of the caregiver's functioning, such as family relations and standard of living, are measured on a four point scale ranging from "0 = not at all", to "4 = considerably".

Procedures. Patients at the geropsychiatry unit were approached by the first and third authors, who explained the study and asked for their participation. Consent for permission to examine medical records (for referral problem), and to contact the primary caregiver was also obtained. The interview time with each patient consisted of about one half hour.

Caregivers were initially contacted by phone by the first author, who explained the study and asked for their participation. If the

caregivers agreed to participate, the caregiver questionnaire and postage-paid return envelope was sent to them.

All procedures and measures employed in the study were approved by human subject research review committees of both the investigators' university, and the geropsychiatry unit.

Results

Scores on Patient and Caregiver Measures. The means and standard deviations of patient assessment and caregiver measures are shown in Table 2. The patient MMSE mean of approximately 23 is indicative of a

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Table 2 about here

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significant degree of cognitive impairment in the sample, based on Folstein's cut-off score of 24 (Folstein, et al., 1975). The average patient's GDS score of approximately 19 is indicative of mild depression in the sample as well (Yesavage, et. al., 1983). Patient ADL and IADL scores indicated that limitations in activities of daily living varied widely.

Caregivers rated patients' disruptive behaviors, and their own distress level as falling between "not at all distressed" to "somewhat distressed". On the average, caregivers reported low to moderate degrees of burden.

Relations among Patient and Caregiver Measures. Table 3 shows the simple correlations between all measures. Patient depression is

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Table 3 about here

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positively related to IADL limitation and negatively related to disruptive behavior to a small degree. As expected, there was a positive correlation between patient ADL and IADL limitations. Caregiver distress, however, was positively related to ADL and not to IADL. This suggests that ADL and IADL measure different aspects of functional limitation, and that ADL limitation may be more distressful to the caregiver because it reflects more severe and possibly irreversible disability (e.g., limitations in feeding and ambulation). Disruptive behavior, caregiver distress, and caregiver burden were all positively intercorrelated.

Multiple Regression Analyses. A step-wise multiple regression analysis was conducted to examine the relative contribution to caregiver burden of patient status, caregiver perceptions of patient disruptive behavior, and caregiver distress over patient limitations or unsafe behaviors. Table 4 lists the measures that were significant predictors of burden ranked according to beta weights. The significant predictors were patient disruptive behavior, patient ADL limitation, patient MMSE, and caregiver distress; they accounted for 53% of the variance in caregiver burden.

Table 4 about here

Discussion

The results of this study suggest that patient ADL limitations, patient cognitive status, patient disruptive behavior, and caregiver distress over patient limitations and/or unsafe behaviors are important contributors to the burden of caregivers of elderly psychiatric patients. The results are consistent with Grad and Sainsbury's (1968) findings that patient confusion and physical dependency are major predictors of caregiver burden. The results are also consistent with Dieeling and Bass' (1986) conclusions that patients' disruptive behaviors have a direct effect on caregiver burden, with patient cognitive incapacity having a less direct effect. However, the results are inconsistent with those of Zarit and associates' (Zarit et al., 1980) reports of no relation between caregiver burden and patient behavior problems, ADL/IADL limitation, or cognitive impairment.

The picture becomes understandable when patient diagnosis within samples is considered. In the present study and those of Grad and Sainsbury (1968) and Deimling and Bass (1986), the samples consisted of heterogenous groups, two of which included psychiatric patients with more than one diagnosis. By contrast, Zarit and associates focussed their work on demented patients only (some diagnosed with Alzheimer disease) and their caregivers. Caregiver burden in a sample of more homogenous samples of demented elderly patients may differ from that of a mixed demented and/or psychiatric sample. A

comparison of similar patient and caregiver measures across larger and varied diagnostic groups of elderly patients (e.g., demented, depressed, schizophrenic groups) is needed to ascertain whether various patient behaviors and/or diagnostic groupings affect caregiver perceptions of burden differentially.

In regard to the specific relations among patient status, patient behaviors, and caregiver distress and burden, the present study suggests additional areas of investigation. Several important questions remaining to be answered include: 1) How is caregiver burden related to differences in caregivers' attributions of illness severity in their elderly patients? Does the lack of relationship between patient depression and caregiver distress found here suggest that caregivers perceive depression as reversible or less critical, and/or are depressed patients easier to care for? 2) Similarly, how might caregiver's knowledge of their patient's illness, and the duration and/or stage of the illness (such as in Alzheimer's disease) affect perceptions of burden, as Zarit, Todd, & Zarit (1986) have recently suggested?

Further investigation of caregiver burden or stress as a multidimensional construct, as suggested by Deimling and Bass (1986), is also needed. Although the reliability of the caregiver distress measure used here was not established, it appears to be a related but separate construct from caregiver burden. These data highlight the need for further refinement of the dimensions of caregiver burden,

their patients' illness, particularly if one is interested in developing intervention programs to decrease burden.

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Table 1. Relationship Characteristics of Caregiver to Patient

Relationship	N	%
Daughter	18	39
Son	8	17
Spouse	7	15
(Wife	4	8)
(Husband	3	7)
Granddaughter	5	11
Niece	3	7
Sister	2	4
Nephew	1	2
Friend	1	2
Foster parent	1	2

Table 2. Means and Standard Deviations of Patient and Caregiver Measures

Measure	Mean	S.D.
Patient MMSE	22.9	4.9
Patient GDS	19.8	4.2
Patient ADL limitation[a]	2.0	3.5
Patient IADL limitation[b]	4.6	4.3
Patient Disruptive Behavior[c]	.67	.38
Caregiver Distress[d]	8.5	8.2
Caregiver Burden[e]	1.3	.94

[a] Sum of 8 items with ratings of: "0 = no help needed, 1 = some help needed, 2 = completely dependent on other's help".

[b] Sum of 9 items with above ratings.

[c] Mean based on ratings of: "0 = not at all, 1 = sometime, 2 = most of the time".

[d] Sum of 17 items based on ratings of: "0 = not distressed, 1 = somewhat distressed, 2 = very distressed".

[e] Mean based on ratings of: "0 = not at all" to "4 = considerably distressed".

Table 3. Relations among Patient Status, Patient Behavior, Caregiver Distress, and Caregiver Burden (Ns range from 40 to 51).

Pt. GDS	.11					
Pt. ADL limitation	-.13	.09				
Pt. IADL limitation	.11	.27*	.66***			
Pt. Disrup. behavior	-.12	-.27*	.04	-.21		
C.G. Distress	-.13	-.04	.45***	.01	.56***	
C.G. Burden	-.18	-.11	.29*	-.04	.54***	.61***
	Pt. MMSE	Pt. GDS	Pt. ADL	Pt. IADL	Pt. Dis. Beh.	C.G. Distress

* $p < .05$

** $p < .01$

*** $p < .001$

Table 4. Significant Predictors of Caregiver Burden

Variable	Beta	Signif.	R^2	Signif.
Patient Disruptive Behavior	.47	.01	.31	.001
Patient ADL Limitation	.41	.04	.04	.13
Patient MMSE	.37	.01	.11	.02
Caregiver Distress	.28	.09	.07	.05

Cumulative R^2 = .53